MEETING MINUTES
Nebraska Palliative Care and Quality of Life Advisory Council
May 6, 2019
1:00 p.m. to 3:00 p.m.
Omaha, NE

Members in Attendance:
Holly Adams
Marcia Cederdahl (via Conference Call)
Linda Rock (via Zoom)
Stacie Sinclair
Todd Sauer
Sabrina Schalley

Staff:
Christine Esch
Andrea Wenke

Guests:
N/A

Agenda Topic	Key Points	Action Items (if any)

Call to Order and Approval of Minutes	• Todd Sauer called the Nebraska (NE) Palliative Care and Quality of Life Advisory Council meeting to order at 1:25 p.m. He referenced the Open Meeting Act, which was posted where everyone could read:
	Open Meeting Act Location Announcement: In accordance with Section 84-1412 of the Nebraska Revised Statutes, a copy of the Nebraska Open Meetings Act is located on the counter near the door.
	• Sabrina Schalley moved to approve the minutes; Holly Adams seconded.
	• Council members voted for Stacie Sinclair to serve as Council Vice Chairperson.
	• There are two Council vacancies; the NE Department of Health and Human Services (DHHS) is still waiting to hear from the Governor's office. Council members agreed that the priority gap is the payer perspective and suggested soliciting nominations from WellCare or Blues of Nebraska if there are no relevant applicants in the pool.
	  o Editorial note: On June 4, 2019, Governor Ricketts announced two new appointments to the Council, Lori Molzer, RN, CHPN, and Denise Woolman. Now that these slots have been filled, there remains an opportunity to increase Council engagement by inviting external stakeholders to our public meetings. Initial suggestions in the "Action Items" column.
		• Select Council members to invite key stakeholders to participate in the Council:
		  o Becky Wisell
		  o Rep from Blues of Nebraska and/or WellCare
		  o Rep from the Nebraska Hospital Association
		  o Nebraska Cancer Coalition

Review of Palliative Care Council Webpage	• Recent updates to the DHHS Palliative Care webpage include a new image on the landing page, a few new links, and the subcategorization of the "Resources for Providers" to break out "Tools and Resources" and "Professional Membership Associations."	• Council members to provide any updates to Andrea Wenke • Andrea Wenke to post February meeting minutes on the website,

Agenda Topic	Key Points	Action Items (if any)

	• Council members agreed on a new procedure in which the NE Palliative Care and Quality of Life Advisory Council will post the meeting agenda on the website before each meeting, and the approved meeting minutes after each meeting. Anyone who is on the website listserv should receive a notification when new materials are posted.
	• Council members were pleased with the overall appearance of the website, including how it appears on a mobile device; however, they noted a few concerns and suggestions:
	  o Some of the content reverted to previous versions or dropped off with the full DHHS website update.
	  o The Palliative Care page is several levels down from the main navigation, which means it is unlikely that people will find it if they are not specifically searching for it. Since it is cross-cutting, palliative care should be referenced and hyperlinked in multiple areas across the DHHS site (e.g., any diagnosis-specific pages/resources). The NE Hospice and Palliative Care Association (NHPCA) can provide a direct link to the DHHS website to help direct people.
	  o There have been some technical issues with the new website and caching information, including several "Page Not Found" notes. Unfortunately, there is not much the DHHS team can do at this time.
		confirm that people on the listserv are notified
		• Andrea Wenke to follow-up with IT about how to optimize search
		• Andrea Wenke to send Marcia Cederdahl the direct link to the DHHS site so NHPCA can link directly
		• Andrea Wenke to determine why the Council page changes haven't been reflected
		• Stacie Sinclair to send Andrea Wenke a list of pages on the DHHS site where it might be appropriate to reference palliative care

Voting on Regulatory Definition	• Marcia Cederdahl and Stacie Sinclair articulated the need for a definition of palliative care in the state code and/or regulations beyond the one contained in the hospice regulations. Following discussion on the relative merits of two palliative care definitions from the Center to Advance Palliative Care (CAPC) and the Centers for Medicare and Medicaid Services (CMS), the Council voted to use CAPC's definition. Marcia and Stacie will follow up with the Department on the next steps.	• Marcia Cederdahl and Stacie Sinclair to contact Becky Wisell regarding the next steps to update and/or insert the definition of palliative care into the state code/regulations
NE Palliative Care Landscape Study	• Council members decided to table this discussion for the August meeting.	• N/A
Opioid Position Statement Debrief	• Several Council members reviewed the revised opioid position statement and provided feedback. The primary concern was conflicting numbers on the scope of opioid misuse/ abuse from the legislature, DHHS, and the Governor's office, and the fact that how these figures were gathered might impact perception of the problem and future action. All ultimately agreed the phrasing in the statement was fine and voted to accept the paper and begin circulating once the testimonies are finalized. • Todd Sauer suggested that the publication of the paper might provide an opportunity to meet with the Governor and Nebraska legislators about this topic and provide progress on the Council overall.	• Stacie Sinclair to finalize testimonies • Shirley Pickens-White to provide Stacie Sinclair with DHHS disclaimer language • Stacie Sinclair and Marcia Cederdahl to request meeting with Senator Kolterman • Todd Sauer to work with DHHS staff to request meeting with the Governor

Agenda Topic	Key Points	Action Items (if any)

Planning and Education for Palliative Care Month	• National Hospice and Palliative Care Month will take place November 2019. In order to ensure action, Council members agreed it was important to begin planning in May, including drafting materials and contacting relevant stakeholders. Sabrina Schalley and Holly Adams volunteered to take the lead on planning potential activities for the month. Ideas included:
	   o Add a luncheon to the NHPCA-initiated proclamation.
	   o Get photo with the Governor and/or Senator Kolterman on August 5.
	   o Connect with the American Cancer Society (ACS), Nebraska Cancer Coalition (NC2), and any other relevant partners to see if they are willing to promote palliative care.
	   o Social media promotion from DHHS, NHPCA, ACS and others using the National Hospice and Palliative Care Organization's (NHPCO) materials.
	   o Issue a press release from DHHS, NHPCA, and ACS that promotes the month and website link.
	   o Contact the Lincoln Journal Star (Cindy Lang-Kubick) and Omaha World Herald to see if they would be willing to do a piece.
	• In addition to National Hospice and Palliative Care Month, Council members discussed opportunities to promote the Council throughout the year. Ideas included tabling at DHHS public health events (e.g., the Public Health Conference, Minority Health Conference, and Re-Charge for Caregivers). Marcia Cederdahl and Stacie Sinclair also discussed the possibility of presenting on palliative care to the various Boards of Health in Nebraska.
		• Sabrina Schalley to work with a social work student on drafting a press release
		• Sabrina Schalley and Holly Adams will lead the task force to propose Palliative Care Month activities
		• Todd Sauer to work with Shirley Pickens-White to schedule meeting with Governor Ricketts on the same day as the August meeting for a picture
		• Marcia Cederdahl and Stacie Sinclair to work with Becky Wisell on strategy for presenting to NE Health Care Boards

Next Meeting	• Several Council members noted conflicts on August 5, 2019 and proposed to reschedule to August 12, 2019. Once DHHS confirms this date works for Council members, Marcia Cederdahl will confirm that space is available at the Nebraska Health Care Association Offices in Lincoln, NE.
	• Proposed Agenda Items
	   o Update on definition progress
	   o Hospice and Palliative Care Awareness
	      ▪ Plan for National Hospice and Palliative Care Month
	      ▪ Plan for palliative care presentation to NE Boards of Health
	      ▪ Status of meetings with Governor Ricketts, Senator Kolterman, and others
	   o Palliative Care Landscape Study
	   o Proposal to begin biannual Council Report
		• DHHS staff to confirm if everyone is available on August 12
		• (Pending confirmation) Marcia Cederdahl to confirm if NHCA offices are available

Public Comments	• N/A	• N/A

Meeting Adjourned at 3:09 p.m.
Meeting Minutes: Stacie Sinclair